

In our Words...

In the fall of 1999, self-advocates in Vermont were asked to help identify training priorities for their support workers. Six forums that were attended by more than 100 self-advocates were held in communities around Vermont. In each meeting, attendees were asked to think about a hypothetical new worker, and then to think about what that worker would need to know and how they would acquire the information. Some self-advocates were accompanied by support staff who were asked to contribute their comments after self-advocates had had a chance to speak. Staff comments are reflected separately.

July, 2000

KNOW ABOUT ME

Know who I am

- I have a boyfriend.
- I have a job and want to keep it.
- I take care of my own home by mopping the floor, cleaning my house, making my own bed.
- I am an artist -I like to paint.
- [I] work at the hospital, convalescent center, Meals on Wheels, Senior Center.
- [Know] what the person is like.
- Knowing the things you like to do.
- Your history.
- Tell her about me.
- I am honest.

Know what my hopes and dreams are and how to support me to achieve them:

- Find an apartment to share with L.
- Get a job; get to my job; help with my job.
- Own my own restaurant.
- Go on a vacation with my boyfriend.
- See my father.

Know how to teach me, or how to find someone who can teach me, what I want/need to know:

- To use Braille.
- To use a computer.
- Teach her how to help people.
- The laws and rights for people with disabilities, MY RIGHTS.
- American Sign Language.
- Facilitated Communication.

- How to save my money.
- Teach her how to use the store, use a washing machine, cook, teaching each other.
- Learn what to eat/not to eat.
- There to help you - shopping, show me how to use the laundry, how to use the stove and oven.

Know what is important to me, what I like to do, and how to support me in doing it/getting there

- I want to be myself.
- Help me to help other people who can't get out (Meals on Wheels volunteer job).
- Teach me how to do different things I've never done.
- Help someone out – do lots of stuff – healthy foods.
- Taking me to rock concert – helps me with my drawing.
- Jigsaw puzzles; go dancing; listen to country western music; Carly Simon; Richard Simmons; painting; arts and crafts.
- My favorite foods are cheeseburgers, hot dogs, french fries, and sodas: how to cook, help me order and make them.
- Which church I go to.
- I go to COPS meetings (self-advocacy).
- I like to do everything.
- Build birdhouse for Alix.
- Exercise with me.
- Self-advocacy meeting.
- Take me places, out to lunch, go for a cruise.
- Help me with laundry, shopping, go have fun, sometimes do things that I like to do.
- Go for rides.

Know what things I need help to do

- Take me shopping.
- Help me get new stuff.
- Help with medications.
- We need her [Sarah] to help us do stuff we don't know how to do.
- Transportation for people to get to their job.
- To help you with idea.
- Help me learn to do things myself.
- Help, go out walk around, pick berries.
- Need support to do Champlain Voices (self-advocacy group).
- Support to be a board of manager for VPSN.
- Help people out – take them to bathroom.
- Shopping – help pay my bills.
- Help me tie my shoes if I need it, but be with me if I need it.
- Be able to support me on my job - job expert.

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**BE KNOWLEDGEABLE ABOUT WHAT'S IMPORTANT TO ME.**

- Getting services when somebody says, "no, you're not eligible" – you know you don't want to end up in a nursing home.
- Talk about rights.
- Always be an advocate.
- Know different stuff that happens at Self-Advocacy meetings.
- Bring back information about self-determination.
- Help us find jobs.
- Training should be focusing on work rather than focusing on fun.
- Money, funding information.
- What is it like to have a disability.
- Having a disability day – to see what it is like to have a disability – all people have disability.

- BE ABLE TO GET PEOPLE JOBS AND TRANSPORTATION!

## TO BE A BETTER STAFF PERSON

### *Listen to me! Ask!*

- Let consumer talk.
- They should be heard.
- [Know how to listen] – "you have to yell at them because they are deaf".
- Ask us about our life. About operations I just had. I hate the dentist. My dad just got out of the hospital. Get the background.
- Just because I can't see doesn't mean I can't do things on my own.
- If you have any questions, beep me.
- Need to know from the person, the guardian.
- I told them what I need help with.
- Listen to person; Listen to what we tell them and take that person's feelings into consideration.
- Be good listeners.
- Understand workers work for the person not the agency.
- I interviewed the guy – [agency] did background – I decided who to hire.
- I decide what the person needs.

### *Practice Openness, Honesty, and Confidentiality*

- Listen to each other.
- No talking about people behind their backs.
- Need to keep things confidential.
- Minding your own business.
- Keeping a confidence helps earn respect and trust.
- Don't be talking to folks about somebody else.
- Tell it to my face, not behind my back.
- Tell the truth about mistakes.
- We all make mistakes. None of us is perfect.

### *Value my safety*

- Do a background check; know what the hell is going on.
- Check workers records.
- If I don't feel comfortable with the person– that's it.
- No pushy people.
- No America's most wanted.
- No abuse - child or adult.
- No sleeping on the job.
- No alcohol on the job.
- No drinking and driving.
- How to speak to police officers.
- How to call for help – how to stay safe.
- Transportation is hard because you don't know who to trust.
- No more funny business.
- It's good to be with a person you know when things happen. I'm glad a person was there with me who knows me, instead of a total stranger.
- Must be a safe person.
- What my health issues are—that I just had surgery.
- Treat me nice, need to know about seizures.

### *Personal Qualities*

- Teach staff to be dependable.
- Some people smoke, some people don't.
- Fun!
- Experience.
- Listen more. Don't make judgements.
- Job should be their job title.
- Admit mistakes.
- Be lenient with self-advocates.
- She is here to help you.
- Someone about the same age [as me].

- Be on time – especially when you have to go some place.
- Be here at 6 o'clock, 9 o'clock, etc.
- Have patience, kindness, gentleness, goodness and self-control.
- The person should be honest.
- They should like President Kennedy [share interests].
- No shallow minded people.
- Treat people nice.
- Just do it – don't make a fuss – help to do it.
- Respect and Kindness.
- Behave good - how you connect, how you get along.
- Someone that cares. Someone that wants to teach me different things.
- [Someone] that [causes] no more gray hair in my head.
- Be nice, be kind, considerate.
- Don't swear.
- Someone I can trust.

### ***Communication Skills***

- Don't interrupt when other people are talking.
- Eye contact.
- Know to always be nice.
- How you connect with the person is important.
- Sense of humor.
- [Tell me] if I'm doing a good job.
- [Tell me] if I'm doing a really great job.

### ***Value the relationship***

- We have fun. You are a team [with me].
- Relationship is important.
- Respect each other's feelings.
- We teach each other.
- I would like to get to know the person [worker]. T. seems like a nice person. She has a lot in common. She likes animals. Animals have feelings as much as humans.
- Teamwork.

- Have mutual respect.
- Grow when you are with friends.
- I taught Liz to do towels.
- Trust.
- Learn about how we get respect.
- Treat us nice.
- BE TRUSTABLE means do what you say you are going to do.
- Trust takes time—workers need to make a commitment to time.
- If I spend all my money loan me money and I'll pay you back.

### ***Do unto others...***

- Calm me down. Try to work it out if I'm upset.
- If I have a problem, go see Sarah (staff). Sarah should talk to me and listen to me.
- Good teacher: kind, considerate, pretty much listens to me, tries to figure out how to make it better for me.
- Treat me right - don't get after me.
- When you get after me I get mad.
- Everybody needs help – not be mean – be nice.
- Handshake – hello – phone – ask questions, to your family.
- We all make mistakes; NOBODY IS PERFECT.
- When I make a mistake take my feelings into consideration.
- Try to work it out or correct it.
- Let go and try things differently.
- Leave me alone while when I'm upset.
- How to help me be comfortable when I need it.
- Smile – when I'm having a bad day.
- Need time out for yourself. Try to work it out (conflict).
- Everyone is different.
- Sometimes leave me alone for a while when I need to relax.
- Everybody has a right to do what they want to do, not do what they don't want to do.

## **HOW SHOULD STAFF LEARN THIS?**

- From us. I'm teaching R. and she's teaching me.
- I decide what the person does.
- Trip to Pennsylvania. Self Advocacy Conference.
- I will tell the worker.
- I will in my ISA meeting.
- Individual is the teacher.
- Admit that they are wrong - admit that they are human. Learn from their mistakes.
- Recognize self-advocate is a trainer at the GH. She does new staff orientation and teaches staff to work with housemate. Get paid for this training.
- Show her around the house and stuff like that.
- I asked questions, interviewed the person, I hired the person.
- Learn from us.
- I should choose who is hired. It should be up to self-advocates to tell them what we expect of them.
- Workers get their best training from self-advocates.
- Learn from self-advocates.
- Job descriptions - Make sure they learn from individual what to do.
- Staff should fix their own mistakes. Do it over again.
- Trusting people.
- I have fired staff if they didn't do what I said.
- Everybody has the right to individuality.
- I wouldn't hesitate to tell them they made a mistake.
- I would teach them – or guardian – parent or whoever is primarily responsible.

## IDEAS FOR TRAINING FOR SELF-ADVOCATES

### *I want to learn more about:*

#### *Directing my services...*

- Train us how to be the boss.
- How to hire your own person.
- Interview – need training on how to interview – need training on how to say what we want.
- How to "be a teacher" and direct support workers.
- How to develop job descriptions for support workers.
- How to tell people when they have made a mistake.
- (We need to) Learn how to interview people.

#### *Communication and Relationship Skills...*

- Learning how to be willing to listen.
- Admitting mistakes.
- How to not burn bridges with people (businesses, landlords).
- Talking things through.
- How to present - go on stage.
- How to speak up.
- How to make friends instead of enemies.
- How to be better listeners.
- How to be more flexible.
- How to be more truthful about our own mistakes.
- Developing trusting relationships.
- How to help other people.

#### *Everyday Stuff...*

- How to read better.
- How to cook, do laundry, grocery shop, budget, woodworking, math, science, Greek mythology.
- Driving a car.
- Job hunting.
- Count money.

- Safety around machines and tools.
- How to use computers.
- How to run a video camera.
- First Aid.
- Art class.
- More about photography.
- To cook - really good.
- CPR.

#### *To be safe...*

- To be safe in your community.
- Street smarts - Springfield Police Department.
- Self-defense.

#### *Citizenship...*

- Want to learn more about government.
- How to be active in government.
- Learn how a bill becomes a law.
- How to vote.

#### *The rules...*

- Expectations.
- Staff to tell me what the rules are.
- If we didn't have people to guide us, we would be in trouble.
- What happens at staff meetings.
- Learning more about our rights.
- I want to learn what's appropriate so I don't get in trouble.

***And...***

- We need community forums about respect.
- Disabilities and handicaps.
- Learn about stuff we never talk about: getting involved, not worrying about my disability, rules, meet people.
- Different things that happen at self-advocacy meetings.
- So other people can learn to walk, pick stuff up; hold on to things in their hands.

***This can be done through:***

- Self advocates teaching together.
- In break-out session at Speaking for Ourselves Conference.

***It also helps to:***

- Need to have confidence to speak up.
- Not afraid to speak up.
- It helps to speak up in one on one situations or small groups.
- Got confidence.
- Not just getting energy but getting the experience.



## **WHAT STAFF SAID IS IMPORTANT FOR STAFF TO KNOW:**

### ***Know the person***

- Get to know the self-advocate's life – hear it from the person.
- Need time to get to know the person and read cues.
- There are some basics, but the rest is very individual.
- Crucial - important to get to know the person - to know him best.
- Know if the person wants one support worker or many.
- Learn from the person who has done it.
- Just reading about the person doesn't work. Have to be part of their whole life.
- S. had a teacher who could recognize from her handwriting when she was upset.
- Very individualized.

### ***Know:***

- Safe places to go.
- People to call.
- Know when I can be in community safely.
- Everything from disability awareness to Pittsburgh Conference
- Safety issues – health issues.
- (How to) Get personal needs met and be safe at the same time.
- Needs to know how/when to assist a person.

## **WHAT IT TAKES TO BE A BETTER SUPPORT PERSON:**

### ***Communication skills***

- Better communication skills.
- All people communicate...we need to figure out how they do.
- Block things out but listen.

### ***Personal Qualities of:***

- Patience
- Be strong
- Flexibility
- Not making judgements.

### ***Knowledge about:***

- Behavioral knowledge.
- Know about the disability.
- Psychology – if you are having a problem – know a little of psychology.

### ***Tips for staff***

- Be flexible. Providing person with the experience of doing, not making them do it.
- Demonstrate – show them how to tell if it is working – body tells all.
- Help people to find way to communicate with others.
- Training that going to self-advocacy events is for all folks, whether they speak or not.
- May need to reach out to others to help.
- Need to know how to assist – don't come up and scare the person.
- I need help and she needs help from me to build a network.
- Know the person's routine.

### ***About relationships***

- Ongoing process of getting to know the person.
- Both trying each other on. Can't force it.

***Staff learn by:***

- Let the individual write the job description. They should have a lot to say.
- If they don't get proper instruction repeat it, go over it again.
- Individual gives instructions and is the teacher.

***If I had to do it all over again....***

- You guys didn't bother to sit me down and say "I didn't have that." I need to know the expectations ahead of time.
- [I got] training from SRS and graduate school. Otherwise I would be sunk.
- I was hired and thrown in from personal experience.
- Enough time is not taken in how to treat someone, confidentiality, how to respect the person, how do we reflect

the person's individuality, communicating with the designated agency, learning about the person.

- Proper instructions might help the staff help you.
- Lot of times I have to fill in and I don't know the person.

***Staff suggestions for self-advocate learning:***

- Making good choices.
- Negotiating what you want.
- How to have a healthy relationship.
- Better communication skills.
- Individualizing job description for me.
- Learning to compromise.
- Reciprocal respect.
- How not to fight, but have productive arguments.